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Title: The double-edged experience of healthcare encounters among women with endometriosis: a qualitative study

by

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Conflict of interest

The authors report no conflict of interest.

Abstract

Aims and objectives: to identify and describe the experience of healthcare encounters among women with endometriosis.

Background: Endometriosis is a “hidden” chronic gynecological disease appearing in every 10th woman of fertile age. Different manifestations of pain are the main symptoms, often leading to impaired physical and mental health, and lower quality of life. Previous research on healthcare experiences among women with endometriosis has focused on diagnostic delay and experiences of encountering general practitioners.

Design: A qualitative, interpretive, phenomenological approach was used.

Methods: We interviewed nine women aged 23-55, with a laparoscopy-confirmed diagnosis of endometriosis. The interviews were recorded and transcribed verbatim. The data were analyzed following the steps of the interpretive phenomenological approach.

Results: Two themes were identified in the interview transcripts: being treated with ignorance and being acknowledged. The essence: “the double-edged experience of healthcare encounters” emerged from the themes. The women’s experience was double-edged since it involved contradictory feelings: the encounters were experienced as either destructive or constructive. On one hand, the destructive side was characterized by ignorance, exposure and disbelief. On the other hand, the constructive side made the women feel acknowledged and confirmed, boosting their self-esteem.

Conclusions: The new and important aspects of the findings are that the experience of healthcare encounters is for the first time expressed as double-edged: both destructive and constructive. The experience was of specific importance as it affected the women’s perceptions of themselves and of their bodies.

Relevance to clinical practice: The information about the constructive side of the experience is of clinical valuable for all healthcare professionals (nurses, midwives, doctors)

encountering these women, as it provides a new level of understanding of the experiences.

The findings demonstrate both psychological and practical aspects that can help professionals to improve the encounters.

What does this paper contribute to the wider global clinical community?

- Provides a deep insight to both destructive and constructive experiences of all endometriosis-related healthcare encounters with nurses, midwives, and doctors.
- Identifies and describes a new level of understanding of the experience.
- Reports specific strategies that can be valuable for healthcare professionals who are aiming to create constructive experiences among this group of women.

Keywords

endometriosis, dysmenorrhea, healthcare encounter, experience, healthcare professionals, qualitative study, phenomenology

Introduction

Menstruation is part of female life over almost 40 years, and can be seen as a sign of health (Mayes et al. 2011). It has been suggested that there is an “etiquette of menstruation” in many societies, whereby menstruation is perceived as a potentially stigmatizing attribute that needs to be concealed (Seear 2009, Johnston-Robledo & Chrisler 2011). Within this menstrual concealment exist the symptoms of endometriosis, a “hidden” chronic disease. Due to the menstruation-like symptoms, endometriosis is often normalized and trivialized, both by healthcare professionals (HCPs) and by the women themselves, leading to diagnostic delays (Culley et al. 2013, Seear 2009). The research on healthcare experiences among women with endometriosis is limited, but indicates that they often have problematic encounters with HCPs

(Ballard et al. 2006, Huntington & Gilmour 2005, Cox et al. 2003). Therefore, in order to improve the clinical nursing and medical care for these women, we need more information about the experiences of their healthcare encounters.

Background

Endometriosis is a condition appearing in about 10% of all menstruating women, characterized by endometrial cells growing outside the uterine cavity. Some women with endometriosis do not have symptoms at all, but endometrial cells outside the uterine cavity may cause irritation, inflammation and scar tissue in the sites where the endometrial cells have implanted, often leading to symptoms such as dysmenorrhea, dyspareunia, subfertility and pelvic pain (Ballard et al. 2008, Dunselman et al. 2014). In addition to the physical symptoms, many women suffer from impaired mental health and lower quality of life (Facchin et al. 2015).

Lack of awareness of endometriosis as a condition, and the perception that menstruation pain is “normal” can cause a delay in seeking medical care at the individual level. When women finally seek care, the diagnosis is often further delayed at the medical level (Culley et al. 2013). Although the diagnostic delay from symptom onset to diagnosis, ranging from four to 12 years, is well-documented (Hadfield et al. 1996, Hudelist et al. 2012, Husby et al. 2003, Santos et al. 2012), little research has been done to examine the reasons for the delay. In the last decade, women’s experiences of the diagnostic delay were explored in a small number of qualitative studies, focusing on women’s experiences of meeting general practitioners (GPs) (Ballard et al. 2006, Cox et al. 2003, Denny 2004, Denny & Mann 2008). However, women with endometriosis are likely to encounter a wide range of different professions when seeking medical care for their symptoms. To our knowledge, no study has previously examined women’s experiences of encountering other HCPs than GPs., such as

nurses, midwives and gynecologists. The aim of this study is to identify and describe the experiences of healthcare encounters among women with endometriosis. We contribute to the limited literature on experiences of this often “invisible” patient group.

Methods

Design

This qualitative study was conducted using an interpretative phenomenological approach. Phenomenology was chosen as a method because we aimed at understanding the lived experiences of healthcare encounters of women with endometriosis. This specific qualitative method often generates detailed and rich interviews, digging deep into the core of the lived experience and consequently enabling a deep understanding for the studied phenomenon (Moustakas 1994). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used as a guide in the reporting of the study (Tong et al. 2007).

Participants and setting

Twelve women were invited to participate in the study. Three gynecologists, who at the time were in charge of the women’s endometriosis treatment, invited the women to participate. One gynecologist worked at a university hospital, and the two others worked in central hospitals. A purposive sampling was used, meaning including women fulfilling the inclusion criteria (Lincoln & Guba 1985). Inclusion criteria were: being Swedish-speaking, over 18 years of age and with a laparoscopy-verified diagnosis of endometriosis. The women were consecutively invited after medical appointments with the gynecologists. These appointments did not have to be related to endometriosis. The gynecologists gave the 12 women oral and written information about the study. After permission from the women the first author telephoned them. The women were again informed about the study, the confidentiality, and their right to withdraw their participation at any time. They were also informed that the

gynecologists who had initially invited them would not be told whether they participated or not. Four of the women declined to participate as their medical condition prevented them to perform an interview. Eight women gave their written informed consent to participate in the study. One pilot interview was included, resulting in a total of nine women. The women were 23-55 years old (median 37 years). Six women had a partner, and three were single. Five of the nine women had children. One woman worked full-time, seven worked part-time (25-80%) and one was on sick leave. They had received the endometriosis diagnosis median 10 years (range 1 – 34 years) prior to the interviews.

Data collection

Prior to data collection, two pilot interviews were conducted to practice the interview technique and to test the interview questions. One of the women giving the pilot interviews was recruited from the first author's work-place, and the other was a friend of a friend. They received the same information on the study as the other women, and gave their written informed consent to participate. These interviews were transcribed and discussed by the research team. One of the pilot interviews contained rich and meaningful information, and was therefore included in the analysis.

The first author conducted the interviews between October 2013 and February 2015 at a time and place chosen by the women. Six interviews were performed in the women's homes and three in a separate room at a hospital library. All the interviews started with some small talk, and then the open-ended question "Can you please tell me about your experiences of your endometriosis healthcare?" Probes such as "Can you give an example?" or "Can you clarify that?" were used to get a deeper understanding and to clarify parts of the interview (Lincoln & Guba 1985). The interviews lasted for 33-113 minutes (median 64 min). They were audio digitally recorded and transcribed verbatim. A bilingual linguist translated the quotes presented in the findings. Words in bold were emphasized during the interviews.

Data analysis

The interviews were analyzed according to Moustakas' modification of the Stevick-Colaizzi-Keen method, adding interpretation (Moustakas 1994). The transcripts were read several times, and significant statements describing the experience were considered. These statements, called meaning units, were highlighted, and overlapping statements were deleted. The meaning units were then clustered into themes, and a textural description and labeling of each theme was made. The next step was to reflect on the variation and the structure of the themes, and to adjust and define the meaning of each theme using the researcher's interpretations of the text. These steps were repeated for each transcript. Finally, the textural and structural descriptions of each theme were integrated into general themes. From the general themes, the essence was identified; i.e. the core meaning of the experience (Moustakas 1994). Three of the researchers performed data analysis separately. Then they discussed and agreed on the themes and the essence.

Ethical considerations

The study was performed in accordance with the ethical principles within medical science (World Medical Association 2013). The Regional Ethical Review Board in [removed for blinded review] approved the study (Dnr 2011/344-31; date of approval: 06 February 2012).

Results

During the analysis, we identified two general themes that were brought together into the essence: the double-edged experience of healthcare encounters, which is the described and interpreted structure of the lived experience of the women diagnosed with endometriosis.

Being treated with ignorance

Looking back at their experience of healthcare encounters, the women described a long struggle characterized by ignorance, i.e. exposure, disbelief, and lack of knowledge. The women had to struggle with exposing the most private parts of their lives to many HCPs:

baring their health, their souls, and their bodies. They felt mentally exposed when having to confide their symptoms to the HCPs, describing how pain and bleeding limited and controlled their daily lives. Most women feared having a serious disease or a malformation that the HCPs were unable to detect. They felt as if they were alone in the world with these symptoms. In this vulnerable situation, it was distressful to be disbelieved by HCPs whose duty was to help them. The women often encountered the attitude that they exaggerated or imagined their symptoms or had low pain thresholds. The insinuation that psychological factors or former abuse enhanced the symptoms, was insulting to some of the women.

“You have to in some way **convince** them that it is like this and that (//) They think that you exaggerate, and you need to try hard so that they believe you, because they don't. You experience that immediately, that they don't believe you.” (Woman 9, diagnosed six years ago)

Having to undergo repeated gynecological examinations, which are often painful to women with endometriosis, made them feel exposed in a physical way. As a gynecological examination was part of the routine investigation, they had no other choice than to subject themselves to it.

“To be exposed, that is something you don't want to risk, so every time it is like a mental procedure, the sense of exposure. Well, it's almost like an abuse, it is something you don't want to do but you **must**.” (Woman 5, diagnosed 20 years ago)

In the pre-diagnosis encounters, HCPs were focused on finding an “easy explanation”, for example infections, miscarriage, or irritable bowel syndrome. When the symptoms did not disappear, the HCPs resorted to normalizing and trivializing the problems. Women were told that menstrual pain was normal for every woman to endure. The women felt invisible as HCPs did not seem interested in understanding them when they gave their accounts of having

to live alone, not being able to have relationships because of pain during intercourse or fear of infertility. Some women perceived the HCPs as distant and nonchalant: they sighed, tapped their fingers on the table, avoided eye contact, and responded in a monotone voice, using a discourse that was incomprehensible to the women.

“I was given advice like ‘start exercising or something’. It made me feel as if I was being ridiculed.” (Woman 7, diagnosed five years ago)

The women felt that they were dependent on the HCPs’ competence since these controlled such an important part of their lives. Sometimes the women experienced that the HCPs lacked basic knowledge about endometriosis. The women felt at their most insecure when the doctor put the burden on them by asking “How do you want me to help you?” The insecurity left them disillusioned, on the edge of despair, drifting without a goal, not knowing where they were heading.

“I asked: ‘What is the goal, where are we heading and what is the next step if this doesn’t help?’ I never got an answer. And then they just said ‘There is no plan’. I thought it was really strange. There **should** be a plan, shouldn’t there? There should be something because there is hopelessness when you are having this pain...It is the worst when you are in this situation, and there is no plan.” (Woman 8, diagnosed five years ago)

Being treated with ignorance made some women feel apathetic, and a sense of hopelessness grew. Others were prompted into continuing the search for an HCP who would believe them and confirm them.

Being acknowledged

In contrast to the feelings of being treated with ignorance, the women also spoke of encounters where they had been acknowledged, i.e. they felt confirmed and visible. The common factor in these experiences was a feeling of being listened to and being believed by

competent HCPs. During constructive encounters, women could say exactly how they felt, without being judged. When they felt confirmed, they no longer had to try to convince the HCPs of their symptoms. They felt less exposed, both when telling HCPs personal things, and when it came to the physical exposure during examinations.

“She always comforts you and explains things, and that is so comforting, that you may complain more and she understands you anyway.” (Woman 2, diagnosed 14 years ago)

The HCPs’ ability to instinctively know what kind of persons the women were was an important part of being acknowledged. One woman considered herself as a humorous person, and therefore appreciated HCPs with whom she could joke. Other women described themselves as too shy to ask questions during the doctor’s round. They were thankful to the nurses who came to them after the round to answer questions. Women noticed that good people skills often went hand in hand with a good pedagogic ability. HCPs who could convey useful information and knowledge could change women’s lives. When the HCPs could guide women towards verbally expressing their sensations, the women felt their self-esteem growing, as they had received the tools to make their symptoms visible to the HCPs. HCPs with high social competence and a good pedagogic ability in addition to detailed knowledge about endometriosis were the most likely to make the women feel acknowledged. If the HCP lacked any of these skills, the women often experienced insufficient support and trust.

“He sort of explained to me, saying ‘Try and press down your bottom, try to relax’. And this with the visceral musculature, I got an explanation for that, and I also felt that it improved a bit, well breathing away the pain, so it didn’t hurt as much as before, because I had been given new understanding.” (Woman 6, diagnosed 34 years ago)

Essence: the double-edged experience of healthcare encounters

When exploring the lived experience of healthcare encounters among women with endometriosis, the essence, *the double-edged experience*, was identified. The women's experience was double-edged since it involved contradictory feelings: the encounters were experienced as both destructive and constructive. All women had experienced destructive and constructive encounters, but some had more experience of one side than the other. Since the disease affected the women's whole existence and had consequences for essential parts of their lives, the experience of healthcare encounters was important. The responses they received during the encounters affected their own thoughts and perceptions about their bodies.

Many encounters were experienced as destructive since the women felt that they were treated with ignorance. Moreover, the destructivity was linked to feelings of invisibility, disbelief, and the risk of mental and physical exposure. It was destructive to encounter HCPs who lacked knowledge and who dismissed the "hidden" symptoms as part of normal female life, considering menstrual pain as "bad luck" rather than a sign of a potentially serious disease.

"And then I sought help, but you were almost treated like an idiot when you called the healthcare services. Menstrual pain is something all girls have. Well, just take some painkillers and it will pass." (Woman 3, diagnosed one year ago)

On the other hand, the constructive experiences made the women's self-esteem grow, as they felt confirmed and visible. Being acknowledged after many years of destructive encounters could change the way the women felt about themselves. The constructive experiences were related to women getting a deeper comprehension of the symptoms and the symptoms' influence on their lives from physical, mental and sexual aspects. This comprehension was a result of a broader perspective from healthcare: a holistic approach that made it possible to

reflect on the symptoms in a philosophical way, focusing on psychological and emotional aspects.

“Earlier there was just endometriosis, there was not a thought that there was a human being behind this endometriosis. // F (doctor) who actually asked me about how this affected me as a woman... It was **so relieving**; suddenly I had the answers! Just getting that information was immensely important. This was a turning point for me as a woman.” (Woman 6, diagnosed 34 years ago)

Being diagnosed with endometriosis was experienced as a mixed blessing, which demonstrates the feeling of double-edginess. On one hand, the women felt relieved to be given an explanation after many years of uncertainty. They felt acknowledged when it was made clear that the symptoms were real and not the results of low pain thresholds or imagination. Some women expressed triumph to the HCPs who had formerly disbelieved them. Getting the diagnosis did not make the symptoms disappear, but it became easier to handle them and to accept them as part of their lives. On the other hand, some women found themselves angry and sad about the suffering they had undergone, which in part could have been avoided if they had been taken seriously many years earlier.

The moment when they received the diagnosis was traumatic for several women. They found that the HCP lacked empathy when giving them the information about the disease, particularly information regarding its effect on fertility.

“And then he said loud and clear in the ward what they had found during the surgery, but the only thing I remember was that he was talking about bloody rags that had grown together... It was really distressing since I was there to check infertility //Adding to the violation, there were three other women on the ward listening to it all.” (Woman 4, diagnosed 10 years ago)

Some women spoke of experiences in the grey area between the two sides; encounters that were neutral, i.e. neither destructive nor constructive, or that were experienced as both destructive and constructive at the same time. One example of a grey area situation was the experience of getting a diagnosis. It was a conformation to receive an explanation of the symptoms, but at the same it was somehow destructive to be given information in a blunt or insensitive way.

“It was a good experience, mostly, but there was a large amount of information at once and I had a lot of thoughts then. Will I never have children? The doctor started to talk about adoption at the same time she first talked about endometriosis.” (Woman 1, diagnosed 15 years ago)

Discussion

The main finding of this study was that healthcare encounters were experienced as double-edged. All women had experienced the two sides of healthcare: the destructive and constructive sides. The destructive side was characterized by ignorance, exposure and disbelief. The side, which made the women to feel acknowledged, confirmed, visible, and which boosted their self-esteem was experienced as constructive. The experience of healthcare encounters was important to the women as it affected their perceptions of themselves and of their bodies.

The identification of the experience as double-edged is, to our knowledge, unique. The limited former research has mostly reported a single-sided negative picture of the experience (Ballard et al. 2006, Cox et al. 2003a, Denny 2004, Denny & Mann 2008, Moradi et al. 2014) This study gives insight into the constructive side of the experience, something that other studies only briefly mention.(Cox et al. 2003a, Cox et al. 2003b, Moradi et al. 2014) When Cox et al. (2003b) describe taking control and turning to alternative medicine as strategies

that make women feel empowered, it is not the result of constructive healthcare encounters, but the result of dissatisfaction with orthodox medicine (Cox et al. 2003b). Moradi et al. (2014) state that women had both negative and positive experiences of the HCPs, but positive experiences are described only as: “*Some women reported that their doctors were really sympathetic, understanding, and had time to talk*” (Moradi et al. 2014, p 6). In our study, the women painted a more vivid picture of the constructiveness, as they specifically described how they reached a new level of comprehension and self-esteem. Constructive experiences made women grow as human beings, as women, and as patients. These findings are consistent with the concept of patient empowerment: the process of patients asserting control over factors affecting their lives (Kolcaba & Kolcaba 1991). Gaining opportunities to experience control has been shown to contribute to wellness (Wallerstein 1992, Siwe et al. 2006), which concurs with the women’s experiences in this study.

Our findings agree with previous qualitative research on difficulties when encountering GPs. The mental and physical exposure, the diagnostic delay, and the normalization of symptoms as “part of normal female life” seem to be experiences shared among women with endometriosis worldwide (Butt et al. 2007, Culley et al. 2013, Riazi et al. 2014, Moradi et al. 2014)

One may ask why the difficulties of giving women adequate care remain, despite the disease being increasingly visible and gaining more attention in public and in healthcare settings. The feelings of being treated with ignorance could to some extent be explained by symptoms being camouflaged as a “normal” part of menstruation, making it difficult for HCPs to detect pathology by history alone. Seear (2009) suggests that the difficulties in detecting endometriosis can be explained by the stigmatization of menstruation itself, and the fact that women avoid disclosing menstrual irregularities due to this stigma. According to Seear, endometriosis care can be improved by moving away from the discussion about

distinguishing between ‘normal’ and ‘abnormal’ menstrual cycles, as this approach is not grounded in an understanding of *why* menstrual irregularities are normalized. Detecting menstrual ‘abnormalities’ will not suffice if society keeps dissuading women from disclosing menstrual problems in the first place (Seear 2009).

With this in mind, there could be benefits in trying to create a more open social conversation about menstruation irregularities, especially menstrual pain as a serious and quite often pathological process. This is something that could be considered as one mission of the HCPs encountering women in their daily practice. An approach where women are fortified with knowledge and interest could contribute to strengthening the constructive side of the double-edged experience.

A strength of this study is that it is the first to focus on women’s overall experiences of healthcare encounters. The use of a qualitative method to identify and describe the experience provides detailed data on essential aspects of the phenomenon from the perspective of the women, that could not be captured through a quantitative survey. It is also a strength that the study complies with the COREQ checklist (Tong et al. 2007). The inclusion of nine women might seem a limited number; however, the interviews generated a large amount of rich and informative data, which was sufficient to achieve both depth and width in the analysis. In the literature, a small sample size (5 to 25 participants) is recommended for this type of research (Lincoln & Guba 1985, Kvale 2009).

In qualitative research, trustworthiness is used to describe terms of validity and reliability. The methods used to establish trustworthiness in this study were reporting the audit trail (i.e. describing every step of the data collection and analysis), and using quotations to illustrate the themes and to show that the findings were grounded in the women’s stories. The first author had a pre-understanding of the phenomenon, having worked as a nurse-midwife at a gynecology clinic. This pre-understanding enriched the themes and essence. To

avoid over-interpretation, the research team analyzed the data separately, discussed the analysis and found agreement in the interpretation. The results of qualitative research are not intended for generalization, but the results of this study might be transferable to other women with endometriosis in similar contexts.

Conclusions

This study contributes to the limited literature on experience of healthcare encounters among women with endometriosis. The most important finding is that the experience of healthcare encounters is for the first time expressed as double-edged: both destructive and constructive. Additionally, the experience of the encounters was deeply important to the women as it affected not only the perceptions of their physical condition, but also their self-esteem and the perceptions of their bodies, and their sexuality.

Relevance to clinical practice

The information about the constructive side of the experience is a new and interesting finding for healthcare professionals, as former studies have reported mostly negative experiences of healthcare encounters. This brings a new level of understanding and provides practical insight in how nurses, midwives and doctors can improve the care of this group of women. The findings demonstrate both psychological and practical aspects that be used to create constructive experiences among the women.

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